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RESEARCH REPORT

The impact of communication on healthcare involvement for people living with motor neurone disease and their carers: A longitudinal qualitative study

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Abstract

Background: Communication and cognitive impairments are known barriers to shared decision-making. Most people diagnosed with motor neurone disease (MND) will develop a motor speech impairment over the disease course. Some will develop cognitive, linguistic or behavioural disturbance. Despite this, the impact of communication and cognitive impairment on personal healthcare decision-making in MND is not well known.

Aims: This exploratory, longitudinal study aimed to capture the perspectives of people living with MND (plwMND) and family members on managing their healthcare with, or in anticipation of, a communication impairment.

Methods & Procedures: Semi-structured interviews and functional assessments were conducted with plwMND and family members over one to three time points between December 2017 and January 2020. Participants were recruited from a specialist MND clinic using a maximum variation sampling approach. Interview transcripts were analysed using trajectory data analysis: a matrix-based approach for thematic analysis of longitudinal data. The study was underpinned by interpretive descriptive methodology.

Outcomes & Results: A total of 19 plwMND with a range of MND phenotypes and 15 family members were recruited. Disease progression and participant withdrawal resulted in attrition, however 12 plwMND and seven family members participated at all three time points. Consistent cognitive screening was not feasible, which limited the opportunity to explore the impact of cognitive change. An overarching theme 'Communicating takes effort' was identified and illustrates the efforts required to compensate for, or circumnavigate, impairments to maintain involvement in healthcare. Assistance from family and accommodation from healthcare professionals (HCPs) was needed for ongoing engagement.

Where plwMND were dependent on alternative communication devices, this assistance was essential and primarily carried out by family members. Despite these efforts, the quality, quantity and accuracy of communication were sometimes compromised. Participants equated good communication with receiving good healthcare, and some expressed anxiety in the anticipation of being unable to express their needs to healthcare workers.

Conclusion & Implications: Communication impairment has a direct impact on healthcare involvement. This study demonstrates the effort required by plwMND and their carers to maintain or maximize ongoing involvement. This effort may not always be visible to HCPs. This information may prompt clinicians to consider the best ways to conduct clinical consultations to accommodate patients' abilities. Compromised communication experiences can be moderated by accommodations and support from HCPs and appropriate adjustments in the health system. Asking patients about their communication preferences and needs, allowing extra time and conducting multidisciplinary sessions are examples of such support.

KEYWORDS
dysarthria, longitudinal, progressive neurological disorders, qualitative

What this paper adds

What is already known on this subject?

- Communication and cognitive impairments are known contributors to negative health outcomes and barriers to shared decision-making generally. The existing literature in decision-making in MND does not address the specific impact of these impairments on personal healthcare involvement for plwMND and their carers.

What this paper adds to existing knowledge?

- This paper reports the findings of a research project that interviewed 19 plwMND and 15 carers on one to three occasions over a 26-month period to obtain their perspectives of the impact of communication on healthcare involvement. Whilst a priori the intention was to look at both communicative and cognitive decline, only the former was achieved. The effort and often 'invisible' activity undertaken to manage or maintain involvement in healthcare is identified. Communication impairment requires support and accommodation, otherwise healthcare involvement can be compromised. Results show participants may associate effective communication with good healthcare.

What are the potential or actual clinical implications of the work?

- Clinicians may wish to use these insights from plwMND and their carers to guide adjustments to their professional practice to maximize healthcare

involvement for their patients. Tailored education for different healthcare groups is needed to improve understanding of MND-related communication impairments and supportive strategies so that involvement in healthcare is not compromised.

INTRODUCTION

Engaging patients in their healthcare through shared decision-making is a fundamental principle of patient autonomy and patient centred care (Joseph-Williams et al., 2014). Patient (or person) -centred care is considered best practice in complex conditions such as motor neurone disease (MND) where clinical focus is on symptom management and quality of life (Oliver et al., 2017). In addition to healthcare professionals (HCPs), the care team regularly includes family and other informal carers. Patient centred decision-making is enhanced by collaboration in multidisciplinary specialist clinics, which can address the unique nature of MND and the changing needs of patients and families (Hogden et al., 2015). Engagement of patients and families in specialist multidisciplinary teams with appointments tailored to meet their needs to maximize shared decision-making is recommended in MND international clinical guidelines (e.g., National Institute of Health and Care Excellence (NICE), 2016). Shared decision-making requires the willingness of patients to engage in healthcare (Joseph-Williams et al., 2014) and is facilitated by competent communication and cognition. However, communication and cognitive impairments are known barriers to shared decision-making generally (Joseph-Williams et al., 2014) and can limit the involvement of people living with motor neurone disease (plwMND) in their healthcare (Paynter et al., 2020).

Most people diagnosed with MND will develop a motor speech impairment (dysarthria) during the disease (Tomik & Guiloff, 2010) and mild-to-moderate cognitive or behavioural deficits will develop in 25–50% of patients (Abrahams et al., 2014). As cognition supports communication, the impacts of both are important to consider. Dysarthric speech may result from flaccid bulbar muscle weakness or spasticity, depending on the balance of lower motor neurone and upper motor neurone involvement, respectively, in each individual (Tomik & Guiloff, 2010). Speech becomes progressively slurred and slow. Adaptive measures, such as pen and paper, and more sophisticated technologies at first augment and then replace verbal communication. Intelligibility is often also impaired by dysphonia, resulting from MND-related vocal cord dysfunction (Tomik & Guiloff, 2010) or when there is poor respiratory support for speech production as breathing muscles weaken. Individuals with dysarthria and dysphonia can find it hard to communicate in groups or noisy environments or when they are talking with someone with hearing impairment. Emotional lability (pseudobulbar affect) is often associated with an upper motor neurone (pseudobulbar) dysarthria and results in exaggerated laughing or crying which are difficult to control (Oliver et al., 2017). The type and degree of emotion displayed is often inappropriate to the circumstance and can be socially disabling. The person cannot usually talk through these emotions. Embarrassed, they may avoid social contact. Specific language impairments seen in MND often involve verbal fluency and confrontation naming deficits (Abrahams et al., 2014). Receptive and expressive grammatical processing difficulties have been identified in 40% of participants studied (Taylor et al., 2013). However, profiling linguistic dysfunction in MND can be challenging due to the impact of associated speech and motor deficits on assessment tasks (Ash et al., 2015). Language dysfunction has been reported in individuals with MND with normal executive function, meaning that executive dysfunction was not a contributing factor to language deficits (Abrahams et al., 2014; Ash et al., 2015; Taylor et al., 2013).

Changes in cognitive function seen in MND varies from subtle cognitive impairment to frank frontotemporal dementia (Abrahams et al., 2014). Apathy is a common behaviour dysfunction reported in MND (Abrahams et al., 2014). Patients presenting with apathy are often difficult to engage in clinical discussions resulting in a barrier to shared decision-making. Social cognitive deficits such as difficulties recognizing and processing emotions and social cues are reported but can be difficult to recognize in a clinical context (Taylor et al., 2013). A recent review highlighted that the impact of communication and cognitive impairment on personal healthcare decision-making in MND was not well described in the extant literature (Paynter et al., 2019). A total of 76 articles on decision-making in MND were identified but only six addressed the issue of cognitive or communication impairments in relation to personal decision-making (Paynter et al., 2019).

MND progression results in functional deterioration, triggering various healthcare decisions. PlwMND often use a cyclical decision-making process as they react and adapt

to ongoing change (King et al., 2009). Longitudinal qualitative research provides an opportunity to capture adaptation. Prospective understanding of the lived experience may provide insights not obtained from cross-sectional research (Grossoehme & Lipstein, 2016; Sakellariou et al., 2013). Whilst shared decision-making is typically a co-constructed effort with the care team, the focus of this study is approached from the perspectives of plwMND and family members. The intention was to explore the impact of both communicative and cognitive decline, however only the former was achieved. The longitudinal design employed provided researchers with the opportunity to capture the perspectives of plwMND and family members as they lived with their condition and a co-occurring communication impairment or the anticipation of a future communication impairment.

METHODS

Context of this study

This paper is a component of a broader project which explored the lived experience of involvement in healthcare decisions for plwMND and carers. The topic guides (see the additional supporting information) relate to the broader study which explored the decisions that people do, or do not, make about interventions, home modifications, advance care planning, etc., and how and with whom they make those decisions. Study results include how plwMND and carers experience healthcare decision-making (Paynter et al., 2020), and information seeking and healthcare engagement over time (Paynter et al., under review).

This study was undertaken in Victoria, Australia, and recruited plwMND and a family member (described as carer) from a specialized multidisciplinary clinic which services approximately 350 people with MND annually. Potential participants were identified at a clinical meeting and a member of the clinical team (usually the neurology nurse or speech–language therapist—SLT) informed the plwMND about the study. Participants were sampled to gain a diversity of age, gender, MND phenotype, rate of progression and verbal and/or non-verbal communicators, consistent with purposeful maximum variation sampling (Creswell & Poth, 2018) (Table 1). Recruitment occurred over a 10-month period. People unable to converse in English, diagnosed with frontotemporal dementia type MND, or presenting with cognitive or behavioural deficits impacting their mental capacity to provide informed consent (as determined by their treating neurologist) were not approached.

Interested patients were provided with a patient information and consent form (PICF). The first author was available in person or on the phone to provide more information, answer questions, determine willingness to proceed and obtain informed consent. Participants were asked to nominate a family member to take part in the carer interviews. Carers were provided with a PICF and informed consent was obtained by the first author if they agreed to participate. Written consent was obtained on the day of the interview. Carers were important to include in this study because they play an essential role in shared decision-making and in providing care for many plwMND (Hogden et al., 2015). Three participants declined involving family members, and one carer declined to participate (for participant dyads, see the additional supporting

TABLE 1 Longitudinal sample characteristics

Time point	T1	T2	T3
PlwMND ($n =$)	19	15	12
Males ($n =$)	10	8	6
Age (years)			
Range	40–79	41–80	42–81
Mean	63	65	64
MND phenotype ($n =$)			
Amyotrophic lateral sclerosis (ALS)	12	9	7
Bulbar onset ALS	4	3	2
Primary lateral sclerosis (PLS)	3	3	3
Years post-symptom onset (T1)			
ALS/familial ALS including bulbar onset			
Range	1.1–17.6	1.7–18.3	2.8–6.5
Range[a]	1.1–4.8	1.7–5.3	
Mean	2.9[b]	3.5[b]	4.7
PLS			
Range	3.8–8.4	4.4–8.9	5.6–10.1
Mean	5.8	6.3	7.5
ALSFRS-R[c] (score of 48 indicates unimpaired function)			
Range	10–44	11–43	1–41
Mean	32	31	29
Carers ($n =$)	15	12	7
Males	5	3	2
Age (years)			
Range	38–73	39–74	44–75
Mean	59	59	62

Notes: [a]Participant 17.6 years post-symptom onset at T1 was excluded from the range calculation.
[b]Participant 17.6 years post-symptom onset at T1 was excluded from mean calculation.
[c]ALSFRS-R, ALS Functional Rating Scale (Revised) (Cedarbaum et al., 1999).

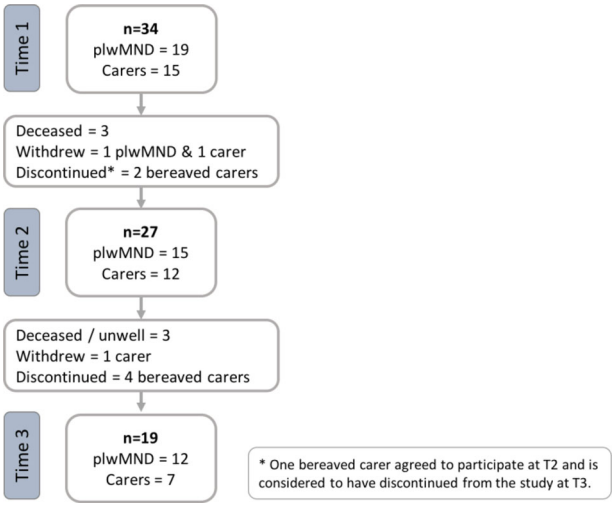

FIGURE 1 Interview sample at each time point [Colour figure can be viewed at wileyonlinelibrary.com]

information). One participant responded to the study information poster placed in the clinic waiting room and emailed the primary researcher directly. Only two potential participants contacted declined to be involved in the study citing health issues or insufficient time to commit to the project. Ethical approval was given by the Calvary Health Care Bethlehem Research Ethics & Ethics Committee (reference number 17081701) and the University of Melbourne's Behavioural and Social Sciences Human Ethics Sub-Committee (reference number 1750285).

Research sample

A total of 34 participants (19 plwMND and 15 carers) were interviewed by the first author between December 2017 and January 2020 (Table 1). Participants were interviewed at baseline (T1) and again at approximately 6 months (T2) and 14 months (T3). The progressive nature of MND meant that some participants passed away during the duration of the study or were too unwell to participate. Attrition was expected and was the rationale for the recruitment sample size which is greater than typical for qualitative research (Thorne, 2016). Three participants died between T1 and T2 interviews, and a further three participants were either too unwell to participate or died between T2 and T3 interviews. Three participants declined further involvement in the study; one plwMND and one carer when approached for T2 interview, and one carer when approached for T3. One bereaved carer participated in an interview at T2 (Figure 1).

Most interviews were conducted in-person in participants' own homes. A total of 65 interviews were conducted in total; five were conducted by telephone (one T1, two T2 and two T3). Some participant dyads were interviewed separately as intended, and some were interviewed jointly at their request. When interviews were conducted jointly, the first author commenced the interview acknowledging the risk that some participants may not fully disclose their opinions due to the presence of the other participant. Participants were given the opportunity to be interviewed separately if they considered this may be an issue; none chose to do so. At the conclusion of the joint interviews, participants were provided with another opportunity to express any opinions privately however none chose to take up this opportunity. A total of 49 interviews were conducted individually and 16 jointly (for time point breakdown, see the additional supporting information). Only participants who consented to be involved were present for interviews.

Participants with MND presented with a range of verbal communication abilities throughout the study (Table 3). Participants presented with normal speech processes or detectable speech disturbance (ratings 4 and 3 on the ALS Functional Rating Scale (Revised)—ALSFRS-R) in the majority of interviews. A total of 13 interviews were conducted with participants with moderate-severe dysarthria or who had lost functional speech (ratings 2 and 1 on the ALSFRS-R). Participants reliant on communication aids were provided with questions in advance and responded with preliminary answers via email (Madsen et al., 2019). In-person interviews allowed for focused follow-up questions which were answered using writing, text-to-speech tablet application or eye-gaze communication device.

Cognitive screening via the Edinburgh Cognitive and Behavioural ALS Screen (ECAS) (Abrahams et al., 2014) was administered to measure change in cognition and behaviour over the course of the study. Cognitive screening was conducted where possible, but was not feasible with every participant at every interview. This was especially evident at T3 interviews where fatigue was prominent. Participants using eye-gaze augmentative and alternative communication (AAC) had to be excluded as the ECAS tool could not be administered in that format in English, at the time of the research. Due to an incomplete data set, cognitive and behavioural scores have not been included but are provided in the additional supporting information.

A total of 19 participants (12 plwMND, seven carers) participated in all three interviews, seven (three plwMND, four carers) participated in two interviews, and seven (four plwMND, three carers) in one interview (Table 2). Single interview data have been included, despite the longitudinal methodology, because they offered rich insights into the impact of communication and/or cognition on decision-making. To preserve anonymity, the gender-neutral singular pronoun (e.g., they or them) is used. On occasion, quotations substituted with 'they' or 'them' will subsequently read ungrammatically with the singular verb

TABLE 2 Interview sample per time point

Time point	*n* = plwMND	Face-to-face or telephone interview	Number of plwMND who discontinued	Reason for withdrawal
T1	19	All face-to-face		n.a. (baseline)
T2	15	All face-to-face	4	3 = death 1 = declined further participation
T3	12	1 telephone	3	3 = death ± unwell
	***n* = carers**		**Number of carers who discontinued**	
T1	15	1 telephone		n.a. (baseline)
T2	12	2 telephone	3	1 = declined further participation 2 = bereaved carers[a]
T3	7	1 telephone	5	1 = declined further participation 3 = bereaved carers 1 = T2 bereaved carer[a]

Note: [a]Except for one bereaved carer, carer participants whose family members died or were too unwell to participate were not asked to continue. One carer, bereaved following the T1 interview, agreed to participate in a T2 interview. This carer is subsequently considered to have withdrawn from the study at T3.

tense. It was our preference to retain the rest of the quotation as spoken. T1, T2 and T3 indicates at which time point the quote occurred, and '(w)' indicates the response was written or typed.

Data collection

Data comprised transcripts from semi-structured interviews, demographic information and assessment of function (including speech function) via the ALS Functional Rating Scale (Revised) (ALSFRS-R) (Cedarbaum et al., 1999). Semi-structured interviews used interview guides (see the additional supporting information) which provided structure and consistency to interviews but allowed participants to discuss their experiences in their own way (Liamputtong, 2013). The interview guide was developed as a result of issues raised in the decision-making literature and background meetings with expert clinicians. Three pilot interviews were conducted: a volunteer with a chronic health condition but not MND, a plwMND regularly involved in medical student training, and a carer of a plwMND. The latter two interviews were included in the data set. To improve interview coherence and flow, some wording and sequencing of interview questions were revised following the pilot interviews and as issues were identified during data analysis (Liamputtong, 2013).

All interviews were conducted by the first author, audio-recorded, transcribed, de-identified and entered into NVivo 12 (QSR International) for collation and management. Two interviews were not recorded due to a technical error; in these cases, the field notes taken during and after the interview were verified with the participants and used for analysis. Interviews lasted on average 50 min with a range of 30–75 min. As fatigue is a common experience for plwMND, the first author maintained sensitivity to changes in body language or response latency that may indicate fatigue. Participants were regularly offered the opportunity to take a break or cease the interview.

Methodology

The method used in this study was underpinned by interpretive description methodology (Thorne, 2016). Interpretive description is situated in social constructionist epistemology and allows for descriptive findings with clinical applicability. This methodology strives for a sound description that represents patterns and relationships within the researched phenomena that have clinical relevance (Thorne, 2016). It has been successfully used to explore communication disorders (Bright et al., 2020) and patient experiences in ALS (Madsen et al., 2019). In order to focus on individual experiences over time, a trajectory data analysis approach was applied (Grossoehme & Lipstein, 2016). Participants were recruited at different time points post-diagnosis and with varied disease status therefore time point comparison, as used in a cross-sectional approach, would have been unfeasible (Grossoehme & Lipstein, 2016).

Data analysis

Participants' demographic data were summarized using descriptive statistics (Table 1). ALSFRS scores are presented to further describe the sample and report deterioration experienced by plwMND throughout the study; speech scores (Table 3) and total scores (see the

TABLE 3 Longitudinal speech ratings

Notes: ▲, Interview 1 (T1); ■, interview 2 (T2); ●, interview 3 (T3).
ALSFRS-R speech score definition: 4 = normal speech processes; 3 = detectable speech disturbance; 2 = Intelligible with repeating; 1 = speech combined with non-vocal communication; and 0 = loss of useful speech.
ALSFRS-R, ALS Functional Rating Scale (Revised) (Cedarbaum et al., 1999).

additional supporting information). Interview transcripts were analysed using matrix-style analytical approaches; the framework method (Ritchie et al., 2014) together with trajectory longitudinal data analysis (Grossoehme & Lipstein, 2016). Analysis was divided into two stages: an initial cross-sectional analysis of T1 interviews followed by a longitudinal analysis across the time points where data were available.

The framework method involves: data familiarization; initial thematic framework construction; indexing and sorting; reviewing data extracts and revising the thematic framework; data summary and display; and category construction and description (Ritchie et al., 2014). The trajectory analysis used time-ordered, sequential matrix style structure to allow for both visual and systematic examination of the longitudinal data (Grossoehme & Lipstein, 2016). This showed how individuals or issues compared at different time points (Grossoehme & Lipstein, 2016). Data analysis commenced with data familiarization. A deliberately diverse selection of participants was chosen at the start of the analysis to aid with the inductive coding process and development of the thematic framework. The longitudinal analysis involved reading all interviews for each participant consecutively multiple times. The initial thematic framework was constructed following open, inductive coding of 28 T1 interview transcripts. PlwMND and carer transcripts were initially analysed sequentially, that is, all plwMND interviews were analysed first, followed by carer transcripts. Concurrent analysis of plwMND and carer transcripts occurred during the last stage of framework analysis (i.e., category construction and description) and during data interrogation and synthesis (Thorne, 2016).

The data within the matrices were interrogated and synthesized to identify themes related to the impact of communication and/or cognition on healthcare involvement by considering a particular issue within cases and across cases to identify similarities and differences. Close attention was paid to negative cases when comparing issues to ensure that thematic patterns and recurring issues reflected the whole data set (Thorne, 2016). Consistent with interpretive description, the researchers discussed the emerging themes mindful of clinical applicability to support the final interpretation. Direct quotations were retained within the matrix to ensure a reliable link to the source data (Thorne, 2016). Coding of the longitudinal data was completed in NVivo 12 and concurrently summarized onto a coding matrix using Excel (Ritchie et al., 2014).

Rigour

Rigour of this project (Liamputtong, 2013) is demonstrated by methodological congruency, extended engagement with

the data (Thorne, 2016), and clear description of study design, data collection and analysis (O'Brien et al., 2014). The first author (and sole interviewer) completed training in qualitative interviewing techniques and is an SLT with skills and experience to interact with people with communication and cognitive impairments. The first author attended fortnightly MND multidisciplinary clinical care meetings for six months during the recruitment period which provided valuable insights regarding the complexity of patient presentations and interdisciplinary care management. This information provided sensitization to the topic area, and helped inform probing issues during interviews. Furthermore, the researcher checked the health status of participants prior to interviews to ensure contact was appropriate and sensitively conducted (Calman et al., 2013). Emergent concepts were discussed regularly by authors CP and MC to ensure interpretations were defensible and strongly linked to the data source. Interpretation of results was discussed at regular research team meetings by authors CP, SM and HG acknowledging the potential influence of clinical experience and identifying any sources of bias. An audit trail and a reflexive diary documenting data analysis decisions was retained. Themes identified during T1 analysis were member checked with nine participants during T3 interviews; discussions were recorded, transcribed and included in the T3 dataset. Finally, use of thick description, illustrative quotations and a comparison to existing literature all support rigour (Liamputtong, 2013). In this paper the quotations that support the development of themes and subthemes are presented tabulated underneath the explanatory prose (Martin et al., 2015). Regarding data availability, as previously stated, the ECAS scores have been included in the additional supporting information. Interview transcripts have not been made publicly available due to the lack of specific consent for data to be made available and the risk of participants being re-identified.

RESULTS

Disease progression

Although a change in communication function was anticipated, speech deterioration was noted in only five participants (P6, P8, P10, P14, P18) (Table 3), which impacted the opportunity to explore change in the data. Observation of longitudinal change was restricted by both fast-progressing participants (P15–P17) who died before follow-up interviews (note: P13 withdrew from the study) and a group of participants who did not decline over the three time points (P1–P3, P5, P7, P9, P11, P12). None of the participants presented with overt cognitive communication deficits during their interviews, and all were able to participate in the interview without the carer speaking on their behalf.

Seven of the 19 plwMND recruited presented with normal speech processes (score 4) at T1 (Table 3). Six of these participants retained normal speech function, and one participant (P10) with normal speech processes at T1 and T2 deteriorated significantly whereby no useful speech was present at T3. This participant experienced the greatest change in the cohort. A further seven participants (P3, P6, P9, P11, P14, P18, P19) presented with detectable speech disturbance (score 3) at T1; four remained stable for all subsequent interviews. Three participants (P6, P14, P18) deteriorated so that they frequently needed to repeat speech to be intelligible and/or benefited from environmental modification such as quiet space, or extra time to respond due to slow speech rate but remained verbal communicators. Four participants (P4, P8, P15, P16) presented at baseline (T1) with significant communication impairment (score 1 or 0) and used either eye-gaze AAC or written communication via an electronic writing device or pen and paper (for complete ALSFRS-R longitudinal ratings for each participant, see the additional supporting information).

Themes

Analysis identified the ways participants manage their healthcare with an existing communication impairment, or how it is influenced by the anticipation of a future communication impairment (Table 4). 'Communicating takes effort' was the overarching theme identified in data analysis. This theme exemplified the effort and endeavours that plwMND and carers carry out to ensure that plwMND remain engaged and involved in their healthcare, and their perceptions of what HCPs also do towards this endeavour. (No active data collection was obtained from HCPs during this study therefore reports of HCPs efforts are recounted by participants.)

Dealing with symptoms

Communicating in the context of physical weakness related to MND takes effort. The symptoms of bulbar, respiratory and limb weakness resulted in slurred speech, breathlessness, poor breath support to produce speech, reduced vocal loudness, impaired voice quality, difficulty writing and typing and physical fatigue. The resultant communication impairment/s required effort to compensate for or endure (Table 5).

The effort to produce speech (i.e., 'to talk') for participants with dysarthria resulted in reduced the quantity

TABLE 4 Themes

Main theme	Subtheme	Categories/issues contributing to subtheme
Communicating takes effort	Dealing with symptoms	The effort plwMND need to cope with, or compensate for symptoms
	Circumnavigating the impairment	How plwMND do, or do not, circumvent difficulties by adopting strategies or devices
	Being there	Carers need to 'be there' during and outside of healthcare appointments to provide support
	Healthcare professionals' accommodations	Modifications of practice by health services and healthcare professionals to accommodate for changes in communication abilities
	Good communication equates to good healthcare	Perceptions by plwMND of the impact of communication impairment on care

TABLE 5 Subtheme – Dealing with symptoms

Reduced quality and quantity of communication	I don't communicate much [with my general practitioner]. I use short sentences. It's a *real* effort. (P14 T2)
	I use pen and paper or a digital writing device, obviously that restricts what I can say. Answers have to much more terse and it is more difficult to get across complex ideas. (w) (P08 T1)
	Hard communicating. Email and sitting at the computer very tiring. And all this makes it mentally draining as well as affects my ability to express myself and have other people understand what I'm asking. (w) (P04 T3)
Anticipating responses leading to inaccurate interpretation	When I am using the eye gaze communication technology, all too often, people guess incorrectly and record the wrong response or start doing something that I didn't want. (w) (P16 T1)
Acute on chronic communication impairment	Once [they] was a bit brighter [they] was more able to advocate for [themselves], but not in the first few days. When you're sick you can't advocate for yourself. (C06 T2)
Impact for paid carers	When the carer was leaving [they] said to me, 'I'm really worried. I don't know if I've done something wrong, but [Name] doesn't talk very much'. I just laughed and said, 'please, it's not you, it's just too much of an effort for [them] to talk'. And [the carer] said, 'Oh, thank goodness. I was so worried I had done something wrong'. (C05 T3)

and quality of communication. Participants reported asking HCPs fewer questions and their answers to HCPs were restricted. Often opinions and reasoning were not fully expressed. These same issues occurred for participants reliant on written communication (either handwriting or typing on electronic communication devices) where they would provide only superficial responses due to the length of time and effort taken to write and type responses. Participants experiencing dysphonia reported frustration at not being fully understood despite unimpaired speech articulation.

Participants using high-tech communication devices (e.g., text-to-speech or eye-gaze technology) found it frustrating if HCPs inaccurately anticipated or second-guessed responses. This occasionally led to inaccurate interpretations of the message resulting in an incorrect response or making the person feel disempowered leading to compliance. The mental and physical effort required to use digital communication such as email often limited participants' ability to communicate with others, including with their healthcare services or HCPs. This impacted their independence in managing healthcare issues such as dealing with the National Disability Insurance Scheme (NDIS) where communication is frequently complex and lengthy.

Being medically unwell further compromised baseline communication or cognitive skills. This reduced patient autonomy and increased reliance on carers during inpatient hospital admissions. As articulated in the quote in Table 5, a family member participant recounted the experience of a paid carer in their home who had misinterpreted the reason for her client not talking.

Circumnavigating the impairment

PlwMND compensated for limitations in communication function and maintained involvement in healthcare appointments through the implementation of various strategies (Table 6). Personal strategies employed included preparing written questions and answers or having discussions with family in advance of medical appointments. Engagement with support services such as the National Relay Service (an Australian government initiative that allows people with a speech impairment and/or are deaf to

TABLE 6 Subtheme – Circumnavigating the impairment

Strategies employed	I have pre-prepared longer statements and it works well, or discussed it with [spouse] beforehand. (w) (P08 T1)
	I communicate a huge amount by texting and of course you can email on your phone as that works as well. (P18 T2)
Persevering with usual communication style	I really need to learn how to use it [AAC]. At the moment, I have [family] or friends take me [to the GP] and to help translate. I don't know, later on, I might have to ask [the general practitioner] what's the best way to communicate with [them]. (P04 T1)
	I still do that [make phone calls] say, if I've got to go to the doctor. (P06 T2). *Researcher: And what if they don't understand you?* P06: Well if they don't [understand me] I hang up. I hang up.
	Not using communication aids at this stage as I feel it is 'use or lose it' approach and want to use speech etc as long as possible. (w) (P04 T3)
	If it was me, I'd be doing things in dot points, but [they] likes to type everything out perfectly, even though I've already figured out what [they] want to say, [they] still write it all out. (C06 T3)
Delegation of communication tasks	[carer] I've been making all the [clinic] phone calls for quite a while. (C05 T1)
	The process [of applying for support or equipment] is quite arduous for people. I can hardly write anything anymore. My [spouse] is very good but [they're] not educated in English so writing letters and all that sort of stuff has been difficult. (P07 T3)

make and receive phone calls) provided the ability to maintain independence for some. AAC devices, iPads, email and smart phones all enabled circumnavigation and provided an avenue for communication. This allowed independent liaison with HCPs as well as participation in healthcare appointments.

Not all participants chose to circumnavigate their impairments with some persevering with speech despite being minimally intelligible or typing full sentences rather than using predictive text or abbreviations. Continuing to persevere with impaired speech was often justified with a belief that function would deteriorate more quickly if they stopped using speech. The effort to learn and use high-tech communication devices was a barrier to adoption of AAC. Some plwMND delegated management of medical or clinic appointments to others. Adopting this position was not always successful, for example, a barrier to the delegation of all tasks was identified if spouses were not literate in English or digitally literate. This resulted in challenges writing letters, completing online insurance or government forms, and replying to clinic emails.

Being there: the importance of a reliable support person

The support required from others was a frequent necessity for ongoing engagement in healthcare for plwMND (Table 7). Carers 'need to be there', both outside of and during clinical appointments. Carers frequently managed medical and clinical arrangements, as well as telephone calls to and from HCPs or care agencies, for plwMND experiencing dysarthria. Assistance was also required for participants who could use speech effectively but due to poor upper limb function could no longer use written communication.

The timing of when carers adopted supportive roles varied and depended on disease progression and severity. Participants with slower progressing disease managed independently for longer. However, some family members did take on managing clinic appointments and phone calls early on as a way of reducing emotional as well as physical burden.

Carers' assistance with AAC was evident in the use, setup, and implementation of devices and was essential to facilitate communication. For example, in telehealth appointments carers read aloud written responses from the electronic devices that cannot be detected by the telehealth camera. During hospital admissions where staff were unfamiliar with communication devices, carers were needed to be present to setup the technology and show staff how to use it. Carers' involvement with the introduction and implementation of AAC varied with some carers being proactive because they foresaw the usefulness of assistive communication.

Both plwMND and carers reflected on the importance of having family present for medical appointments. Often this assistance was as 'proxy speaker' or 'translator', other times it was more profound than simply translating. Family members provided additional, personally relevant information which was only possible due to the relationship between those involved. Involvement, as described above, often came at the cost of carers' employment, interests, and hobbies. Some carers openly admitted to being in denial of the diagnosis and limited their involvement in healthcare decisions by, for example, avoiding attending

TABLE 7 Subtheme – Being there: The importance of a reliable support person

Support needed outside of appointments	In terms of looking at care agencies I've been making all the phone calls. In part the reason that it's me is because it's phone calls, and verbal communication is the most efficient way. (C06 T2)
	I mean physically trying to fill out [the NDIS] forms is difficult so I help because [they] has trouble writing now. (C07 T1)
Function and perceived burden influences support	I do attend the clinic now. Last year [they] was managing okay on [their] own. [They] needs help now so I normally go. (C05 T1)
	[carer] I've had to make some of the decisions … I feel [they] need less things to worry about, rather than more. (C14 T1)
AAC facilitation	When [they] was in [acute hospital] one of us was always there (C12 T1). *Researcher: Could you have communicated with the doctors without your family?* P16 T1: (Head shake) 'No'. C12: No, [spouse] couldn't have. P16: (w) So [spouse] made sure someone [from the family] was always with me.
	We set [eye gaze] up, and [spouse] says, 'no, I'm not using it. It's too hard.' And I said, 'we gotta keep doing it 'cause one day you're going to need it'. So, I turned off [their] wheelchair and left [them] with the eyegaze. And [they're] swearing at me but by the time I came back and I hear, 'this is great'. [They]'d mastered it. You've got to be cruel to be kind sometimes. (C13 T2)
Being present or available	A lot of it's actually inferring what [they] would want based on having known [them] for all those years, knowing [their] wishes. I can say what [they] want based on just one word whereas someone else might not be able to do that. (C04 T2)
	I can think of the words and I know it but I can't quite bring it to speech. [Child] knows exactly what I'm trying to convey and it makes it easier on those girls [HCPs]. (P18 T2)
	I would be working, because they've asked me back multiple times, but I want my time free for [spouse]. (C11 T1)
Impact of difficulty accepting diagnosis	Because when you're in denial it's much easier to tolerate. This is a sickness where denial can help. (C02 T1)
	Going to the clinic doesn't worry me, it worries [spouse] horribly. [They] just hates going there. [They] didn't go last time. (P01 T2)

clinic appointments or not reading the Motor Neurone Disease Association newsletter. This reported denial and lack of involvement often did not appear to change or reduce over time.

Healthcare professionals' accommodations

As recounted by participants, HCPs and health services accommodated for changes in communication function by modifying usual practice such as emailing or texting patients rather than making contact via telephone calls (Table 8). This allowed plwMND to maintain control and independence in managing aspects of their healthcare over time and disease progression. Participants described clinical environments which accommodated their impairments (e.g., quiet clinic rooms) and staff skilled at understanding dysarthric speech. Furthermore, HCPs allocated extra time, or conducted interdisciplinary appointments to reduce burden on patients. This meant that plwMND with a communication impairment did not have to repeat providing information related to current issues or concerns. Documented care plans written by the specialist clinic were shared with plwMND and family members, as well as other HCPs and services (e.g., case managers). Whilst this was standard practice for all patients with and without communication impairments, it supported plwMND with a communication impairment by eliminating the burden of relaying information verbally to carers or family not present at appointments.

Telehealth appointments offered plwMND the opportunity to access multidisciplinary or even multi-service consultations without the burden of travelling to appointments. These appointments were appreciated but were not without challenges for people living with communication impairment who struggled with the amount of questioning, and having to communicate over a digital platform.

HCP's accommodation of communication impairment with the use of AAC was contingent on their time and their willingness to use unfamiliar technology. Participants' reports regarding this were varied; some HCPs took extra time and made effort to learn and use AAC, whilst others were less willing to do so. In busy clinical contexts, one participant felt the need to comply rather than be viewed as difficult by insisting on the use of AAC.

Mainstream health and disability services did not always accommodate participants' communication needs.

TABLE 8 Subtheme – Healthcare professionals' accommodations

Changes in practice to accommodate change	(w) I'm also happy knowing I can text my doctors etc. Everything is at my fingertips. (P15 T1)
	Two of them [allied health professionals] combined appointments the other day, into a single appointment to save [spouse] the effort of saying the same thing twice. (C14 T2)
Current practice can accommodate communication impairment	I like that there's written care management plans, so you're clear on who does what. … It's actually really helpful to have those updates from each appointment … [and it] helps, too, when there's multiple family members to stay involved. (C04 T1)
	[telehealth] Much better idea, but it's still [challenging]. Questions bombarding. It's a real effort. (P14 T2)
	[The staff] in [the acute] hospital were pretty good too. Issues with doctors trying to communicate quickly because they're in a rush. Nurses have more time usually. (w) (P08 T3)
Communication needs are not always accommodated	So often staff are rushed, I can't always decide on the spot, but sometimes I just comply, I don't want to be seen as a difficult patient. (w) (P16 T1)
	In regard to NDIS plans, always feels rushed and not enough time to get head around it all as very complex. If too many people at meeting, I can't get a word in edgewise. It causes anxiety in anticipation having to deal with these things. (w) (P04 T2)

TABLE 9 Subtheme – Good communication skills equates to good healthcare

Being able to express MND-related needs	For my own safety, I have to tell them [paid carers] what to do. It's kind of a very anxious time because you rely on them. You're at their mercy. (P04 T2)
	Some of the nurses are very, very good, very caring and listen [to my specific needs]. But it is a battle. Lucky I do have good communication skills. If I didn't, I think I'd be in serious trouble. (P05 T2)
	I had a new carer and I was quite anxious because they will not have any training in [communication support] at the agency. I had everything written down. (w) (P04 T2)
Anticipating future barriers and needs	Will [they] be able to get what [they] wants at the time because of the communication difficulties? (C04 T1)
	I'm trying to get everything [legal issues] in order while I'm still able to. (P12 T2)
	I went to my GP about it [voluntary assisted dying legislation]. I said, 'I want to talk about it now while I can, while I've got my faculties'. I'm not demented, I know exactly what I'm saying. (P05 T3)
Deterioration of communicative skills considered a time point	I know when I can't communicate anymore that's when I'll say, '[Spouse] you know what? We better go through this [advance care plan] book'. At this stage, I don't want to think about it. (P07 T2)

Participants reported NDIS planning meetings often had insufficient lead-time to allow for adequate preparation and that complex issues were sometimes difficult to resolve over email. This resulted in anxiety and exclusion.

Good communication skills equate to good healthcare

PlwMND and carers in this study identified a relationship between effective communication and receiving safe and appropriate care. This perception was expressed by people with an existing communication impairment, those without, and those anticipating a future impairment (Table 9). Participants expressed the importance of being able to explain their specific MND-related care needs to healthcare workers and were concerned that without the ability to explain what they needed, care would be compromised. The anticipation of having a new paid carer was anxiety-provoking for a participant with severe dysarthria who reported their paid carers did not receive training in communication impairment support. Some participants with communication impairment reported preparing for new paid carers by writing down specific instructions and care needs in advance to ensure their needs were clearly understood. Also, carers raised concerns about whether their family member would receive appropriate person-centred care from paid carers or the healthcare team when they were unable to verbally communicate.

Anticipatory healthcare planning was evident from participants without existing communication or cognitive impairment. Some participants appointed powers of attorney and discussed voluntary assisted dying with medical practitioners reflecting these processes needed to be completed, or would be easier to complete, with intact cognition and communication. The onset of communication impairment was considered an important time point that would indicate the need to commence planning for future needs and completion of medicolegal paperwork such as advance care plans.

DISCUSSION

This longitudinal, exploratory study describes the personal impact of communication impairments on healthcare involvement for plwMND and carers. The need for reliable support and HCPs who are responsive and accommodating is clearly articulated by participants. Despite broad research in the field of healthcare and communication disorders that evidences issues such as poorer health outcomes and increased risk of preventable adverse events (Baylor et al., 2019), little is known about how communication and/or cognitive impairment impacts healthcare decision-making and involvement in MND (Paynter et al., 2019).

The *effort* required for communication, altered communication style and planning in advance of communicative situations was apparent. The direct impact of a communication impairment on healthcare involvement was evident in diminished quality and quantity of expression; plwMND did not fully express their opinions, ask as many questions and accuracy was compromised when HCPs rushed communicative interactions. The impact of effort has been previously identified in everyday communication for people with acquired dysarthria, albeit in different fields, post-stroke (Brady et al., 2012) and people with Parkinson's disease (Yorkston et al., 2017).

A preference to continue using speech, even when intelligibility was compromised has been reported elsewhere by plwMND as a way to maintain social closeness (Murphy, 2004). Participants in this study did not report specific psycho-emotional issues related to changes to their speech or voice, however there is a strong link between voice and identity (Nathanson, 2017) and this may be a reason for continued use of one's own voice. Further, most speech generating AAC devices use synthesized voice output and therefore lack speech 'identity' (Nathanson, 2017) which may reduce motivation to learn to use AAC. AAC uptake in MND is influenced by numerous factors including access to SLT services, timing of intervention, communication partner attitude and expectations, and complexity of learning to use devices (Ball et al., 2004; Murphy, 2004).

The importance of having a reliable support person both in and outside of clinical appointments was evident in this study. The inclusion of family carers in healthcare decisions is a fundamental principle of patient centred care and has been shown to facilitate patient autonomy in decision-making in MND (Hogden et al., 2013). Consistent with these results, carers assumed communication responsibilities (Hogden et al., 2013; Judge et al., 2019), and provided support for the use of AAC (McKelvey et al., 2012). Furthermore, the value of shared knowledge and familiarity of the communication partner within clinical appointments is reported in other research (Kathner et al., 2015; Murphy, 2004).

Effective communication skills equated to receiving good healthcare according to many participants in this study. They perceived that possessing intact speech allowed them to facilitate or direct appropriate care, and expressed fear and anxiety at anticipating not being able to explain their needs to nurses and paid carers. The anticipation of losing communication skills can have significant psychological impact for both plwMND and their carers although it remains not well understood (Judge et al., 2019). Indeed, plwMND participating in an interview study to explore their experiences of dysphagia (swallowing difficulties), reported that the impact of communication deficits was more of a concern than dysphagia (Lisiecka et al., 2019). PlwMND relate the value of communication skills with patient autonomy (Lemoignan & Ells, 2010). Bereaved carers have reflected that decision-making, such as completing advance care plans (ACP) would best be completed prior to deterioration of communication skills (Preston et al., 2012). Decisions regarding medicolegal issues including advanced care plans (ACP) are an essential component of care management for MND. Intact communication and cognition means that 'difficult' conversations regarding future wishes and end-of-life plans are easier to manage and autonomy is preserved. This is reflected in some participants initiating conversations and/or paperwork regarding these decisions 'while they still can' and some reflecting that deterioration in communication would be a catalyst to initiate planning.

The accommodations made by clinicians and the specialist clinic were essential for plwMND to maintain engagement in their healthcare. Adjustments to practice such as conducting multidisciplinary sessions, allocating extra time to appointments, and communicating digitally were reported as helpful by participants. These accommodations were initiated by HCPs familiar with the communication and cognitive difficulties associated with MND. Clinicians less familiar with MND may have difficulty identifying when and how to adjust consultations

to accommodate communication impairments. Tailoring discussions to meet the communication and/or cognitive needs of individuals are recommended in clinical guidelines although specific strategies or practical advice is not provided (e.g., NICE, 2016). Similarly, Martin et al. (2015) provide recommendations to support decision-making in MND but the strategies do not target communication and/or cognitive impairment specifically. Medical and allied HCPs often receive training in breaking bad news and shared decision-making however intact patient communication is often assumed (Baylor et al., 2019). Having sufficient time to communicate was an important factor promoting inclusion and accuracy of communication for participants in this study, particularly those using AAC. Whilst allowing extra time is not included in the strategies provided by Baylor et al. (2019), they provide a comprehensive range of strategies for HCPs to use with people with a broad range of communication disorders (Baylor et al., 2019).

IMPLICATIONS

For clinicians, these results will raise awareness of the invisible activity undertaken by plwMND and carers, often outside of clinical appointments, to maintain or maximize involvement in their healthcare. With this awareness, clinicians have an opportunity to be more cognisant of how patients and carers cope and compensate for their communication and/or cognitive impairments. They may wish to acknowledge that communication and consultation can occur in alternative ways. Having an awareness of the potential for reduced quantity and quality of communication, clinicians may wish to consider 'how can communication best be supported?' (Judge et al., 2019: 6). The answers to such a question need to accommodate the many contexts and settings where routine, urgent, social or confidential communication for healthcare decision-making occurs.

Tailored education for different health professional groups which is context specific would support HCPs to accommodate communication and/or cognitive impairments. Further research would be helpful to extend our understanding of accommodations made by HCPs to support participants with a communication and/or cognitive impairment and whether it was due to tacit knowledge exchange or education and training. Specific strategies for accommodating communication and cognitive impairments in MND (beyond those provided by participants in this study) would supplement the strategies to support decision-making in MND provided by Martin et al. (2015) and to support communication impairments generally provided by Baylor et al. (2019).

LIMITATIONS

This research aimed to capture the lived experiences of plwMND and their carers as disease progressed and function changed, with a focus on changes to communication and cognition. However, many of the participants in this study did not change as significantly as expected, and some participants died following the interviews, so their likely-altered abilities are not captured in the dataset and explicit change was less evident in the findings. Planned cognitive screening of all participants at each time point was not achieved. Scheduling a second appointment, to accommodate for fatigue to complete the assessment would have assisted in obtaining additional data. Future research could use an observational or ethnographic methodology to explore interactions with HCPs in a more focused manner. Another limitation of the study is that the perspectives of HCPs were not obtained and is identified as a recommendation for further research. Thirdly, all participants recruited were managed at a specialist MND clinic and were English speakers which limit the diversity of experiences obtained and therefore the application of findings.

CONCLUSIONS

This longitudinal, exploratory study illustrates the importance of good communication for good healthcare. It raises awareness of the physical and logistical effort required by plwMND and their carers (primarily family members) to remain engaged in healthcare. Despite the effort invested there can be an impact on the quality, quantity and accuracy of resultant communication. This study clearly shows that communication is everyone's business. Adjusting usual practice by, for example, asking patients about their communication preferences and their existing communication strategies before consultations, allowing extra time and conducting multidisciplinary sessions, using digital communication platforms and providing patients and families with written care management plans will all facilitate healthcare engagement for plwMND. A knowledgeable, responsive and accommodating workforce and health system is needed to mitigate the disability experienced by plwMND with a communication impairment and to reduce the anxiety experienced at the anticipation of communication loss.

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CONFLICT OF INTEREST

The authors report no conflict of interest.

DATA AVAILABILITY STATEMENT

Some results data (e.g., the Edinburgh Cognitive and Behavioural ALS Screen scores) are included in the additional supporting information. Interview transcripts have not been made publicly available because specific participant consent for this was not obtained, and due to the risk of participants being re-identified.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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